Complete Summary

GUIDELINE TITLE

Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders.

BIBLIOGRAPHIC SOURCE(S)

American Academy of Child and Adolescent Psychiatry. Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. American Academy of Child and Adolescent Psychiatry Working Group on Quality Issues. J Am Acad Child Adolesc Psychiatry 1999 Dec;38(12 Suppl):5S-31S. [117 references]

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Mental retardation and comorbid mental disorders including:

- Pervasive Developmental Disorders (PDD)
- Attention-Deficit/Hyperactivity Disorder
- Tic Disorders and Stereotypic Movement Disorder
- Mental Disorders Due to a General Medical Condition
- Schizophrenia and Other Psychotic Disorders
- Mood Disorders
- Anxiety Disorders
- Posttraumatic Stress Disorder (PTSD)
- Obsessive-compulsive Disorders (OCD)
- Eating Disorders

GUIDELINE CATEGORY

Diagnosis
Evaluation
Treatment

CLINICAL SPECIALTY

Psychiatry

INTENDED USERS

Physicians
Psychologists/Non-physician Behavioral Health Clinicians

GUIDELINE OBJECTIVE(S)

To aid clinicians who are called upon to provide mental health services to persons who have mental disorders comorbid with mental retardation.

TARGET POPULATION

Mentally retarded children, adolescents, and young adults up to 21 to 22 years of age, an upper age limit of eligibility for public special education and related services in some states.

INTERVENTIONS AND PRACTICES CONSIDERED

Diagnosis

Comprehensive assessment of mental retardation (MR), including:

- Diagnosis of mental retardation using standardized intelligence testing and evaluation of adaptive skills through testing or clinical evaluation.
- Biomedical evaluation, including family, pregnancy, perinatal, developmental, health, social, and educational history; physical and neurodevelopmental examination; and laboratory tests. Laboratory tests are usually indicated by the findings in the history and physical examination and may include chromosomal analysis (including fragile-X by DNA analysis); brain imaging (CT scan, MRI); EEG; urinary amino-acids; blood organic acids and lead level; appropriate biochemical tests for inborn errors of metabolism.
- Assessment of psychological and behavioral functioning.

Assessment of mental illness in persons with mental retardation, including comprehensive history, patient interview, medical review and diagnostic formulation.

Treatment

Habilitation and treatment of persons with mental retardation, including

- Specific treatment of the underlying condition, if known, to prevent or to minimize brain insults that result in MR (e.g., shunting in the case of hydrocephalus).
- Early intervention, education, and ancillary therapies (such as physical, occupational, and language therapies), family support, and other services, as needed.
- Treatment of comorbid physical conditions, such as hypothyroidism, congenital cataracts or heart defects in children with Down syndrome, treatment of seizures in persons with tuberous sclerosis, etc.
- Treatment of comorbid mental disorders.

Psychiatric treatment of comorbid mental disorders, including psychosocial interventions and pharmacotherapy.

MAJOR OUTCOMES CONSIDERED

Not stated

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The literature review was based on Medline and PsychInfo searches using key words "mental retardation" and "mental illness," "psychiatry," and specific mental illness entities; references from major review articles and book chapters; and books on MR and mental illness comorbid with MR. Additionally, the authors and consultants brought their cumulative clinical experience from years of work with individuals with MR and related systems of care.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not applicable

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Clinical consensus was determined through extensive review by the members of the Work Group on Quality Issues, child and adolescent psychiatry consultants with expertise in the content area, the entire Academy membership, and the Academy Assembly and Council.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Six individuals are acknowledged by name for their review of the practice parameter. These parameters were made available to the entire Academy membership for review in September, 1998, and were approved by the Academy Council on June 27, 1999.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

General Aspects of Mental Retardation (MR)

Assessment of MR

The assessment of a person with mental retardation is typically multidisciplinary. Increasingly, developmental disorders clinics are established in which psychologists may perform cognitive assessment, developmental pediatricians and clinical geneticists may complete physical diagnostic evaluations, and psychiatrists and behavioral psychologists may assess psychological and behavioral function. University Affiliated Programs have been established throughout the U.S. to bring

together such expertise, but available resources will influence the roles of various clinicians in the evaluation process. The comprehensive assessment includes:

- Diagnosis of mental retardation using standardized intelligence testing and evaluation of adaptive skills through testing or clinical evaluation.
- Biomedical evaluation, including family, pregnancy, perinatal, developmental, health, social, and educational history; physical and neurodevelopmental examination; and laboratory tests. Laboratory tests are usually indicated by the findings in the history and physical examination and may include chromosomal analysis (including fragile-X by DNA analysis); brain imaging (CT scan, MRI); EEG; urinary amino-acids; blood organic acids and lead level; appropriate biochemical tests for inborn errors of metabolism.
- Assessment of psychological and behavioral functioning.

Habilitation and Treatment of Persons with MR

The habilitation of persons with MR is based on the principles of normalization and community based care, with additional supports as needed. Federal legislation, for example, the Individuals with Disabilities Education Act (IDEA), entitles disabled children and adolescents to a full range of diagnostic, educational and support services from birth to age 21. Specialized treatments are also provided if necessary, as is done for persons with severe visual and auditory impairment. Additional entitlements may be provided by state laws. The parents of children and adolescents with MR are entitled by these laws to receive support services and to be active participants in treatment planning. Some parents and older patients are not aware of their rights to obtain services. The clinician has an important role in such instances to educate and, if needed, to refer to a "patient advocate" or "educational advocate." In recent practice, children and adolescents are educated in special classes in regular school or in inclusionary programs (in age appropriate regular classes, with additional supports as needed). In the United States, children with MR are now rarely if ever placed in residential institutions and separate schools. Adults with MR of all levels live in the community, in settings varying from their own apartments with supports as needed, to small (4-8 residents) group homes. They are employed in specialized settings or, increasingly, in the competitive job market. Habilitation and treatment include:

- Specific treatment of the underlying condition, if known, to prevent or to minimize brain insults that result in MR (e.g., shunting in the case of hydrocephalus).
- Early intervention, education, and ancillary therapies (such as physical, occupational, and language therapies), family support, and other services, as needed.
- Treatment of comorbid physical conditions, such as hypothyroidism, congenital cataracts or heart defects in children with Down syndrome, treatment of seizures in persons with tuberous sclerosis, etc.
- Treatment of comorbid mental disorders.

Assessment of Mental Illness in Persons with MR

Mental illness is frequently comorbid with mental retardation, with most prevalence estimates ranging from 30% to 70%. Virtually all categories of mental

disorders have been reported in this population. An accurate psychiatric diagnosis provides the foundation for understanding the patient and for treatment planning.

The psychiatric diagnostic evaluation of persons who have MR is in principle the same as for persons who do not have retardation. The diagnostic approaches are modified, depending on the patient's cognitive level and especially communication skills. For persons who have mild MR and good verbal skills the approach does not differ much from diagnosing persons with average cognitive skills. The poorer the communication skills, the more one has to depend on information provided by caregivers familiar with the patient and on direct behavioral observations.

The assessment includes:

Comprehensive History

The history taken from the patient and from several caregivers in different settings covers:

- Presenting symptoms include concrete descriptions of specific behaviors in various situations and settings, their change over time, antecedent events and the way the various caregivers handle them.
- Psychiatric review of systems includes premorbid and current behavioral and personality patterns, adaptive functioning, self-care, communication, and social functioning.
- Details of previous psychiatric treatment, with particular emphasis on medication side effects that could cause the presenting symptoms.
- Past and present educational, habilitative, work programs and living situation: their quality, consistency and appropriateness; availability of supportive services; long term plans for the patient's care.
- Parents/caregivers attitudes to the patient, their understanding of his/her disability, support for growth vs. overprotection.
- Review of past cognitive tests and evaluations, or request for new ones if needed.

Patient Interview

- Ample time must be allotted for the patient interview which typically takes longer than with patients without MR. Sufficient time is needed to put the patient at ease.
- The verbal examination should be adapted to the patient's communication skills and should use clear and concrete language, structure, reassurance, and support. Leading questions and questions requiring yes or no answers should be avoided and the interviewer should ensure that questions are understood.
- Patients with sensory impairments like blindness or deafness must be approached in a manner that recognizes their needs through the use of appropriate interpreters or communication devices.

- Mental status may be assessed in the context of conversation, rather than in a formal examination. It is often helpful to start the interview with a discussion of a patient's strengths and interests, rather than problems, and later focus on the patient's understanding of disability, limitations, and reasons for the referral.
- Nonverbal aspects of the interview include observations of performance on selected tasks, relatedness, expression of affect, impulse control, attention span, activity level, and the presence of unusual behaviors or seizures.

Medical Review

This review should include developmental and medical history, past etiological assessments, and coexisting general medical disorders and their treatments. The latter is particularly important, since undiagnosed medical conditions are frequent in this population and may lead to behavioral symptoms.

Diagnostic Formulation

Data from the assessments should be interpreted in light of developmental level, communication skills, associated handicaps, life experiences, education, and family and sociocultural factors. A particular behavior may suggest an underlying mental disorder if it is a part of a pattern of a defined mental disorder syndrome. The possibility of sexual or other abuse that the patient cannot report, should be considered. A DSM-IV diagnosis (in addition to MR) should be made, if the appropriate criteria are met. The diagnostic statement should include a description of the person's strengths, deficiencies, and needs including intellectual, adaptive behaviors, communication, health, and psychosocial domains. A comprehensive assessment should yield a multiaxial diagnostic formulation with appropriate differential, and supporting evidence for diagnoses should be highlighted.

Specific Diagnosis of Common Comorbid Mental Disorders

Refer to the guideline document for specific diagnosis of common comorbid mental disorders, including:

- Pervasive Developmental Disorders (PDD)
- Attention-Deficit/Hyperactivity Disorder
- Tic Disorders and Stereotypic Movement Disorder
- Mental Disorders Due to a General Medical Condition
- Schizophrenia and Other Psychotic Disorders
- Mood Disorders
- Anxiety Disorders
- Posttraumatic Stress Disorder (PTSD)
- Obsessive-compulsive Disorders (OCD)
- Eating Disorders

Treatment

The principles of psychiatric treatment are the same as for persons without mental retardation, but modification of techniques may be necessary, according to the individual patient's developmental level, especially communication skills. Medical, habilitative, and educational interventions should be coordinated within an overall treatment program. The mental health clinicians should actively participate with other professionals in the development of the various treatment interventions.

The Behavioral Emergency

When the clinician is called to assist with a behavioral emergency, the first task is generally to ensure the safety of the patient and others. For example, in the case of severe self-injurious or aggressive behavior, if the usual attempts at redirection fail and the patient continues to pose an imminent risk, it may be necessary to temporarily employ physical restraint. In some instances this may require admission to a psychiatric hospital. The use of emergency medication may also be considered after adequate diagnostic assessment. Medical causes for an acute behavioral exacerbation must always be considered. It is not uncommon for even simple problems like constipation, infection, or even occult injury to set the stage for behavioral problems. Medication side-effects like akathisia from neuroleptics or disinhibition from sedative/hypnotics can be expressed in aggressive and self-injurious behaviors. When a temporizing measure is necessary, it is generally advisable to utilize a drug with which the patient has had a positive experience, typically a neuroleptic or benzodiazepine. The need for emergency treatment should prompt a comprehensive diagnostic assessment including the evaluation of environmental influences. Approaches should also be considered to prevent recurrence of such emergency situations for a given individual.

Psychosocial Interventions

Persons with MR may benefit from group, individual and family psychotherapy. Concrete goals should be established, with the overall aim to achieve a maximally feasible quality of life. Disruptive behaviors should not merely be suppressed, but replaced with constructive, adaptive behaviors and skills. Patients should learn to understand their own disability, focus on strengths, develop a positive self image, a realistic striving for independence, and age-appropriate social skills. The treatment techniques include focus on current reality, directiveness and structure to maintain focus, and activities adapted to chronological age. A therapist with training in developmental disorders is best equipped to accomplish these goals and to guide the patient to develop his/her own understanding. Therapists should be active, directive, and flexible, perhaps using themselves as examples, and should be prepared to give concrete advice.

Family therapy typically focuses on the parents' identification and support of their child's strengths and independence, and the provision of opportunities for success. Parents of recently diagnosed children need careful explanation of their child's condition. Concrete advice in management and resource finding is important, as well as help in obtaining educational supports to which the child is entitled under federal and local laws. Parents of adolescents and young adults need help in

coming to terms with emergent sexuality, and in emotionally separating and preparing them to move to out-of-family living in the community.

Pharmacotherapy

Medication effects generally are not different from those expected in the absence of MR. The adage, "start low, go slow," reflects the observation that shifts in dose-response in certain contexts are far more likely than changes in the mechanism of action of a compound, for example, persons with Down syndrome may be exquisitely sensitive to anticholinergic drugs, and some persons with MR may be more sensitive to the disinhibiting effects of sedative/hypnotic agents.

There are several problems with pharmacotherapy frequently encountered with persons with MR:

- Some clinicians appear to prescribe medication with inadequate information, aiming, for example, for symptom suppression seemingly without consideration of the potential negative impact on habilitative function or overall quality of life. Risks/benefits for medication appear not to be fully considered (e.g., drugs which adversely affect cognition, either directly or through sedation, appear to be used without clear justification and careful monitoring).
- There is no evidence of informed consent to support the prescription or administration of psychotropic medication.
- Medication appears not to be integrated as part of a comprehensive treatment plan (e.g., there is no evidence of a behavior plan; no evidence of communication between prescribing physician and other therapists; behavioral data are not collected).
- Medication may not appear to be appropriate for the diagnosis of record (e.g., a patient with a diagnosis of a mood disorder is receiving only thioridazine).
- Drug exposure appears to be excessive or poorly justified. Medication appears to be prescribed for extended periods for nonspecific indications for which other active treatments or environmental supports are needed. Multiple representatives from the same medication class and other complex polypharmacy regimens are employed or no attempt can be seen over time to adjust medication doses to document ongoing need or the minimum dose at which a medication remains effective. In some cases treatment effectiveness is never clearly established.
- No evidence can be found for the active monitoring for emergent side-effects, particularly in nonverbal patients.

Treatment Follow-up

A common problem in the treatment of persons with MR is assessing its effectiveness, which may be viewed differently by various caregivers. Therefore, discrete treatment goals should be agreed upon by the clinician and caregivers, as well as target or "index" symptoms. Interdisciplinary collaboration of professionals and caregivers is essential. Various mental health clinicians might function in the team as direct care providers, team leaders, or consultants to other professionals. Among them, clinicians with medically and psychologically oriented training are often prepared to function as synthesizers of treatment modalities of various disciplines. Follow-up includes patient interview/observation and obtaining

comprehensive interim information. If the patient is not experiencing improvement, the accuracy and completeness of the biopsychosocial diagnosis should be reviewed, as well as the consistency of implementation of treatment by the caregivers.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is not specifically stated for each recommendation.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Accurate psychiatric diagnosis and appropriate treatment for children, adolescents and adults with mental retardation and comorbid mental disorders.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

Practice parameters are strategies for patient management, developed to assist clinicians in psychiatric decision-making. These parameters are not intended to define the standard of care; nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results. The ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all the circumstances presented by the patient and his or her family, the diagnostic and treatment options available, and available resources. Given inevitable changes in scientific information and technology, these parameters will be reviewed periodically and updated when appropriate.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

American Academy of Child and Adolescent Psychiatry. Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. American Academy of Child and Adolescent Psychiatry Working Group on Quality Issues. J Am Acad Child Adolesc Psychiatry 1999 Dec;38(12 Suppl):5S-31S. [117 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

1999 Jun 27

GUIDELINE DEVELOPER(S)

American Academy of Child and Adolescent Psychiatry - Medical Specialty Society

SOURCE(S) OF FUNDING

Not stated

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

As a matter of policy, some of the authors to these practice parameters are in active clinical practice and may have received income related to treatments discussed in these parameters. Some authors may be involved primarily in research or other academic endeavors and also may have received income related to treatments discussed in these parameters. To minimize the potential for these parameters to contain biased recommendations due to conflict of interest, the parameters were reviewed extensively by Work Group members, consultants, and Academy members; authors and reviewers were asked to base their recommendations on an objective evaluation of the available evidence; and authors and reviewers who believed that they might have a conflict of interest that would bias, or appear to bias, their work on these parameters were asked to notify the Academy.

GUIDELINE STATUS

This is the current release of the guideline.

An update is not in progress at this time.

GUIDELINE AVAILABILITY

Electronic copies: Available (to members only) from the American Academy of Adolescent and Child Psychiatry (AACAP) Web site.

Print copies: Available from AACAP, Communications Dept., 3615 Wisconsin Ave, NW, Washington, DC 20016. Additional information can be obtained through the AACAP Publication Catalog for Parameters.

AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

- American Adademy of Child and Adolescent Psychiatry (AACAP). Summary of the practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. J Am Acad Child Adolesc Psychiatry 1999 Dec;38(12):1606-10.

Print copies: Available from AACAP, Communications Dept., 3615 Wisconsin Ave, NW, Washington, DC 20016. Additional information can be obtained through the AACAP Publication Catalog for Parameters.

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI on February 28, 2000. The information was verified by the guideline developer on October 18, 2000.

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